

Raised Bill Number 5450 – AN ACT CONCERNING THE PALLIATIVE USE OF MARIJUANA

Sean William Hearn's Testimony
Age 10

My name is Jeff. I am a longtime friend of Sean W. Hearn's family, who reside at 134 Winton Place in Stratford, CT. Sean is a 10 year old boy who has been fighting for his life since he was 5 months old. Sean is living with a very rare and debilitating form of childhood onset epilepsy called Lennox Gastaut Syndrome. Children with Lennox Gastaut Syndrome typically suffer with multi and intractable seizure types. Sean has over 50 seizures a day!

Although Sean is 10 years old, developmentally he is at 6 month level. He is completely dependent on all of his care. He is confined to a wheelchair and unable to sit without someone holding him or stand without equipment. Sean is unable to speak. He is feed via a feeding tube and takes a combination of 5 seizure medications 3 times a day.

Over the course of the past 9 and half years, Sean has seen multiple doctors and have worked with Yale, Boston Children's Hospital, CCMC, NYU and John Hopkins. His medical team have tried to control his seizures through diet (Ketogenic Diet), medications and alternative therapies. With the onset of puberty rapidly approaching (which typically makes treatment even more difficult) the medical team have exhausted all treatment options.

With the number of medications Sean's takes daily there are side effects. The most notable are extreme fatigue and loss of personality. With every new med added, Sean fades away a little more.

The work that is being done with cannabis oil (which contains no more than 0.3% THC) in Colorado and across the country has given families like Sean's a reason to hope.

Sean is the most important thing to his family. Every decision they make directly impacts his health and quality of life. They research everything before considering new treatment options and they do not take the subject of cannabis oil lightly. I ask you to legalize cannabis oil for palliative use by minors, so that this can be a treatment option in Connecticut. More importantly, it would be another treatment option for children like Sean.

I implore you to pass this bill.

Regards,

Jeff Domogala
2 Telo Road
Windham, NH 03087
603-247-9169